FETAL ALCOHOL SYNDROME:

A CALL FOR ACTION IN B.C.

The Children's Commission

FEBRUARY 2001

THIS REPORT IS DEDICATED TO THE MEMORY OF CAROL LEGGE, PROVINCIAL FAS PREVENTION CO-ORDINATOR, CHILDREN'S AND WOMEN'S HEALTH CENTRE OF B.C., VANCOUVER.

CAROL'S REMARKABLE AND PIONEERING LEGACY — BASED ON HER PHILOSOPHY OF RESPECT, UNDERSTANDING, COMPASSION AND HOPE — WILL MAKE A DIFFERENCE IN MANY LIVES FOR MANY YEARS TO COME.

SHE GAVE US HER ALL, AND HER SPIRIT LIVES ON.

LETTER OF TRANSMITTAL

February 2001

Honourable Graeme Bowbrick
Honourable Ed John

Attorney General
Minister for Children and Families

As part of my role as Children's Commissioner and in accordance with the Children's Commission Act, I have prepared this special report, entitled "Fetal Alcohol Syndrome: A Call for Action in B.C."

The report includes the key elements of an action plan that government must implement in order to do a better job of preventing this disability and of supporting children and youth and their families.

Paul Pallan

Paul Pallan
Children's Commissioner

The Children's Commission would like to thank the members of the FAS Forum Planning Committee for their expertise, advice and support:

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The commission also gratefully acknowledges the support of the forum co-sponsors:

Ministry for Children and Families
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Children's and Women's Health Centre of B.C.
Health Canada.

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The cost of waiting until a crisis erupts will be huge. In comparison, the cost of prevention is minimal, as is the cost of early intervention and helping children and families learn to cope with FAS.

1 INTRODUCTION

FETAL ALCOHOL SYNDROME (FAS) is the leading known cause of intellectual disability in children. The damage is permanent. Most children with FAS will never be financially or socially self-sufficient. They are also more likely to be in foster care, require special education, drop out of school early, develop substance use disorders and mental health problems, have trouble with the law, and experience joblessness and homelessness.

FAS is preventable. Programs that reach at-risk groups do reduce the incidence of FAS. Early diagnosis and intervention make a difference in reducing the secondary problems mentioned above.

Children, youth and families affected by FAS enter into many aspects of the Children's Commission's work. Commission staff have reviewed the deaths of children and youth where FAS has been or may have been a factor for the child or the child's parents. Lack of services and supports for children and youth with FAS is sometimes identified in the plans of care for children in foster homes, group homes and other types of government care. The need for more and better programs for children and youth with this disability has also been the subject of a number of complaints received by the Children's Commission.

In fulfilling its role in conducting special investigations and preparing special reports concerning matters affecting children and youth, the Children's Commission is in a unique position to provide leadership and act as a catalyst on the issue of FAS, which affects several ministries and jurisdictions in the province.
In 2000, the commission considered conducting a special investigation into FAS in British Columbia. However, after talking to families, community organizations and professionals working in the area of FAS, the commission realized that what is needed is not more studies, but an integrated plan of action. It became clear that engaging in a dialogue with experts and working together to develop a strategic response would be more productive.

To this end, the Children's Commission convened a group of approximately 60 people who have FAS or have experience working with individuals with FAS for a forum called "Fetal Alcohol Syndrome: A Call for Action in B.C." The forum took place in Victoria on November 23–24, 2000. The list of forum participants is included in Appendix A of this report.

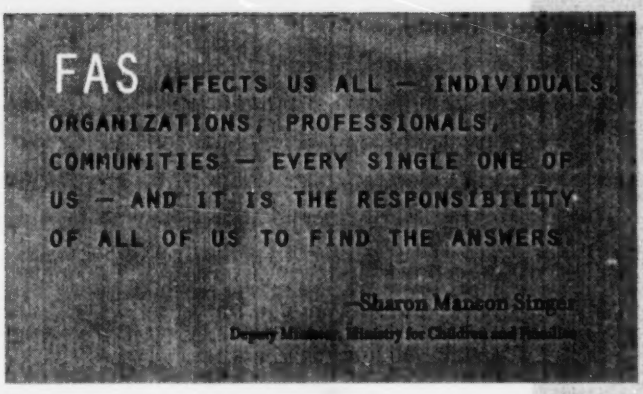
This report is about taking action.

Forum participants were asked to assist the Children's Commission in developing an action plan based on:

- the current health, social justice, economic and human costs of FAS
- current services and supports for people with FAS
- gaps in current services and supports
- effective programs that could provide models for other communities
- strategies for linking B.C. with other provinces and territories on issues related to FAS.

One of the major issues raised by participants was the need to address some of the myths that create barriers and hardships for those living with FAS. Participants also stressed the need to raise awareness about ways in which FAS can be prevented.

This report captures many of the thoughts and ideas expressed at the forum. It contains key information presented, as well as success stories that were heard. Of particular importance are the stories told by members of a panel of young adults with FAS, who started the forum off by focusing on our responsibility and our ability to take action now.


FAS AFFECTS US ALL — INDIVIDUALS, ORGANIZATIONS, PROFESSIONALS, COMMUNITIES — EVERY SINGLE ONE OF US — AND IT IS THE RESPONSIBILITY OF ALL OF US TO FIND THE ANSWERS.
—Sharon Manson Singer

This report is about taking action. The aim of the report is to provide specific recommendations that grew out of the forum and that form the basis for an FAS action plan for B.C. The plan will require substantial political will and commitment to implement. Taking action is not a cost: it will save millions of dollars over the long term, and more importantly, prevent the human tragedies that can result from this preventable disability.

The commission will be closely monitoring the implementation of the action plan over the coming months and years.

2 WHAT IS FETAL ALCOHOL SYNDROME?

FETAL ALCOHOL SYNDROME (FAS) is a medical diagnosis that refers to a cluster of anomalies associated with alcohol use in pregnancy. The three essential traits of FAS are:

- growth restriction
- characteristic facial features, and
- damage to the central nervous system, resulting in neurological abnormalities, developmental delays, behavioural dysfunction and learning disabilities.

While it is difficult to estimate the number of children and youth with FAS, studies suggest that about 140 children are born with FAS each year in British Columbia. FAS is preventable, and it is permanent. Children do not grow out of FAS even with the best family environment and schools.

The costs of FAS are high. FAS-related lifetime costs in extra health care, education and social services per individual have been conservatively estimated at between $1 and $2 million. That means that for the approximately 140 children born with FAS in B.C. this year, between $140 and $280 million in additional funds will be required to care for them over their lifetime. And this will continue every year that FAS rates remain high. The human costs, however, the loss in quality of life, effects on mental health, joblessness, homelessness and even early death, are immeasurable.

OF ALL THE SUBSTANCES OF ABUSE, INCLUDING HEROIN, COCAINE AND MARIJUANA, ALCOHOL PRODUCES BY FAR THE MOST SERIOUS NEUROBEHAVIOURAL EFFECTS IN THE FETUS, RESULTING IN PERMANENT, LIFELONG DISORDERS OF MEMORY FUNCTION, IMPULSE CONTROL AND JUDGEMENT.

A child will not be born with FAS if the mother does not drink during pregnancy.

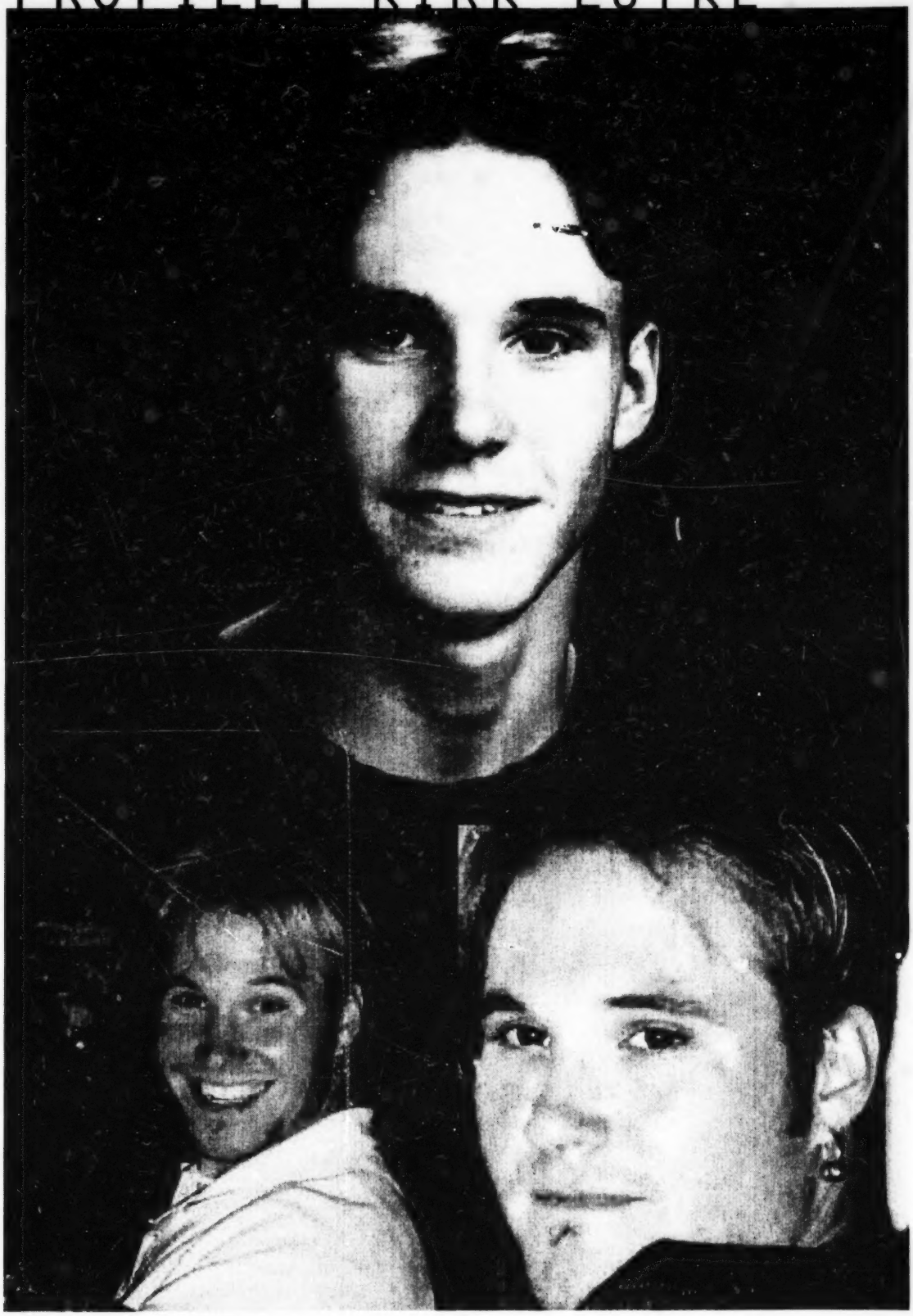
A child will not be born with FAS if the mother does not drink during pregnancy. However, it appears that there are a number of other factors in addition to exposure to alcohol that increase the risk for developing the condition. These factors include parental health, nutrition, poverty, tobacco and illicit drug use, lack of prenatal care, and other socio-economic factors. FAS is therefore not simply about alcoho! abuse. It is a complex issue rooted in the underlying social and economic conditions that influence all aspects of maternal and child health.

FAS IS THE LEADING KNOWN CAUSE OF INTELLECTUAL DISABILITY IN CHILDREN, SURPASSING BOTH SPINA BIFIDA AND DOWN SYNDROME.

WHAT IS PARTIAL FAS?

PARTIAL FAS (FORMERLY KNOWN AS FETAL ALCOHOL EFFECT, OR FAE) REFERS TO CASES IN WHICH THERE IS KNOWN SIGNIFICANT PRENATAL ALCOHOL EXPOSURE, AND AN INDIVIDUAL EXHIBITS SOME OF THE CHARACTERISTICS OF FAS, INCLUDING ABNORMAL FACIAL CHARACTERISTICS AND BEHAVIOURAL AND COGNITIVE PROBLEMS, AS WELL AS EVIDENCE OF ONE OTHER FAS COMPONENT. COGNITIVE AND BEHAVIOURAL PROBLEMS ASSOCIATED WITH PARTIAL FAS CAN BE VERY DEBILITATING AND LEAD TO LIFELONG DISABILITIES. PARTIAL FAS, THEREFORE, IS NOT NECESSARILY A MILDER FORM OF FAS BECAUSE THE SIGNS, THOUGH FEWER IN NUMBER, MAY BE JUST AS SEVERE AS IN FAS.

PROFILE: KIRK LUTKE



KIRK LUTKE, 24, who was diagnosed at age 14 with FAS, came to live with his adoptive family at age 11. "That made an incredible difference in my life," he says. Before that, he and his brother, who also has FAS, lived with their biological parents, who both drank heavily. The boys then moved to a foster family, where they did not fare much better. Kirk's brother is currently in jail.

Kirk has a number of medical problems, including a weakened immune system and a heart condition, both of which stem from FAS. He is on a lifetime disability income.

Kirk had a difficult time in school. "The teachers thought I was lazy, that I didn't care. But I didn't skip one day." Kirk says teachers need to have a lot of patience with children who have FAS. One-on-one tutoring helped him a great deal. His adoptive family was very supportive as well. This kind of attention makes a big difference.

Entering the workforce—if they are able to—is also difficult for people with FAS. "It's hard to open up to employers and tell them that you have FAS," Kirk says. "Communication is a problem." And: "When we do 100 per cent, it looks like 50 per cent to others."

3 FETAL ALCOHOL SYNDROME: MYTHS AND REALITIES

THERE ARE MANY MYTHS ABOUT FAS THAT CREATE BARRIERS AND HARDSHIPS FOR THOSE LIVING WITH IT. HERE ARE A FEW:

MYTH: Behaviour problems associated with FAS and partial FAS are the result of poor parenting.

REALITY: People with FAS or partial FAS don't process information in the same way that other people do. This can lead to behavioural problems.

MYTH: Children affected by FAS will grow out of it when they grow up.

REALITY: FAS lasts a lifetime. However, *early intervention and supportive services* make a difference in reducing the other health, emotional and social problems that can result from FAS, thereby giving people with FAS a chance to be more productive and healthy members of society.

MYTH: Those affected by FAS can be effectively helped by a single agency or discipline.

REALITY: The ongoing special educational, health care and social services needs of those affected by FAS are such that strong inter-agency co-operation and multidisciplinary support are required.

MYTH: The problem will go away.

REALITY: FAS is preventable, but alcohol is so much a part of our culture that it will take a great deal of work to reduce the numbers of people with FAS. Solutions include education and reaching pregnant mothers early—even before pregnancy begins.

MYTH: Women who are birth parents of FAS-affected children had an easy choice not to drink during pregnancy and, through callous indifference, they damaged their children.

REALITY: A drinking problem is never easy to stop. Pregnancy is an excellent time for women with drinking problems to stop or reduce their use of alcohol. They need respect, understanding and caring assistance.

MYTH: FAS is related to race or ethnicity.

REALITY: FAS is related to the use of alcohol during pregnancy. Many mothers who drink during pregnancy are dealing with a history of abuse, poverty, discrimination and limited access to relevant health and social services. The prevalence of FAS therefore might be higher in some groups—not because of race or ethnicity, but because of these other factors.

MYTH: Forcing pregnant women who misuse alcohol and drugs into prisons or treatment centres will prevent continued use.

REALITY: Imposing solutions on a woman will only cause her to feel ashamed and frightened, which may make her less likely to seek out or accept help. It is important to support her as she works towards a chosen and sustainable change for herself and her children.

MYTH: Partial FAS and Alcohol-related Neurodevelopment Disorder (formerly known as FAE) are milder forms of FAS.

REALITY: The symptoms, though fewer in number, may be just as severe as those of FAS.

Adapted from Ann Streissguth, Ph.D., University of Washington, and the B.C. FAS Community Action Guide

WOMEN AT RISK OF HAVING CHILDREN WITH FAS OFTEN LIVE IN POVERTY, HAVE POOR PRENATAL CARE, POOR NUTRITION AND HEALTH, AND PSYCHIATRIC/MENTAL HEALTH AND DRUG USE ISSUES. IN A 1994 STUDY OF 500 B.C. WOMEN IN ALCOHOL AND DRUG TREATMENT PROGRAMS, 80 PER CENT WERE OF CHILD-BEARING AGE. OF THAT NUMBER, 92 PER CENT HAD SUFFERED EMOTIONAL ABUSE, 69 PER CENT PHYSICAL ABUSE AND 51 PER CENT SEXUAL ABUSE. (THESE ARE RISK FACTORS FOR FAS.)

PROFILE: RANADA LUTKE

RANADA was diagnosed with FAS as an infant, and lived in 22 foster homes before the age of five. Now 25, she says "I didn't understand what was wrong with me."

School was always difficult for Ranada, who says she failed Grade 1. Her teacher didn't understand what she was going through. For people with FAS, the bullying that often goes on at schools can be particularly devastating. But dropping out is just as devastating.

"When kids drop out, where do they end up?" she asks. "Look out on the streets..."

Kids need support so they don't end up on the streets. "Kids with FAS need homes," Ranada says. "We need to feel like we're part of the home, and not just there temporarily."

As a child, Ranada was always very tiny and hyperactive, and couldn't sleep. Even now she has trouble handling change, being alone or being in a crowd. People with FAS are at risk for further abuse. Ranada was in an abusive, controlling relationship with a man who made her feel stupid. "People pick out naive people they can control," she said.

Ranada says it can be particularly difficult getting medical care. "Doctors don't have time to listen to us." She needs help getting medical care and has difficulty remembering to take her medication. She also forgets to eat and says the part of her brain that signals that it's time for a meal doesn't connect to her stomach.

She explains that while many people with FAS outgrow the characteristic facial features they were born with, their brains don't work as fast as other people's—and that, though not visible, always stays the same.

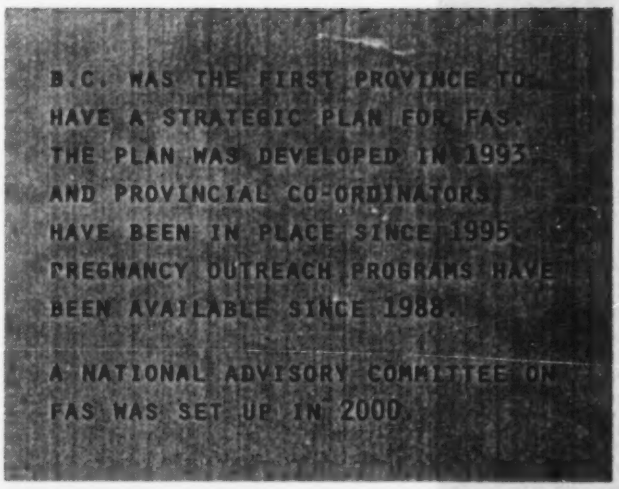
4 SOME CURRENT INITIATIVES

A significant amount of work has gone into dealing with FAS in B.C. Here are some of the current initiatives led by the Ministry for Children and Families:

- The ministry has a number of supports in place to deal with FAS, including direct support for affected children and families and support for front-line organizations such as the FAS Support Network and Sheway in Vancouver.
- An inter-ministry working group developed a draft provincial action plan on FAS prevention and support. The plan has three components:
  - education, awareness and training, which includes public education and prevention work
  - providing the right support for individuals, families and communities
  - research and evaluation.
- The Provincial FAS Consultation Group, a network of B.C. service providers and experts, has created a listing of FAS services and supports across B.C. to help improve information sharing and co-ordination of services. This information is available on the Ministry for Children and Families' Web site.
- The Child Protection Division of the Ministry for Children and Families has developed a video to help adoptive parents deal with FAS. A new foster parent education program includes a special module on FAS and FAE.

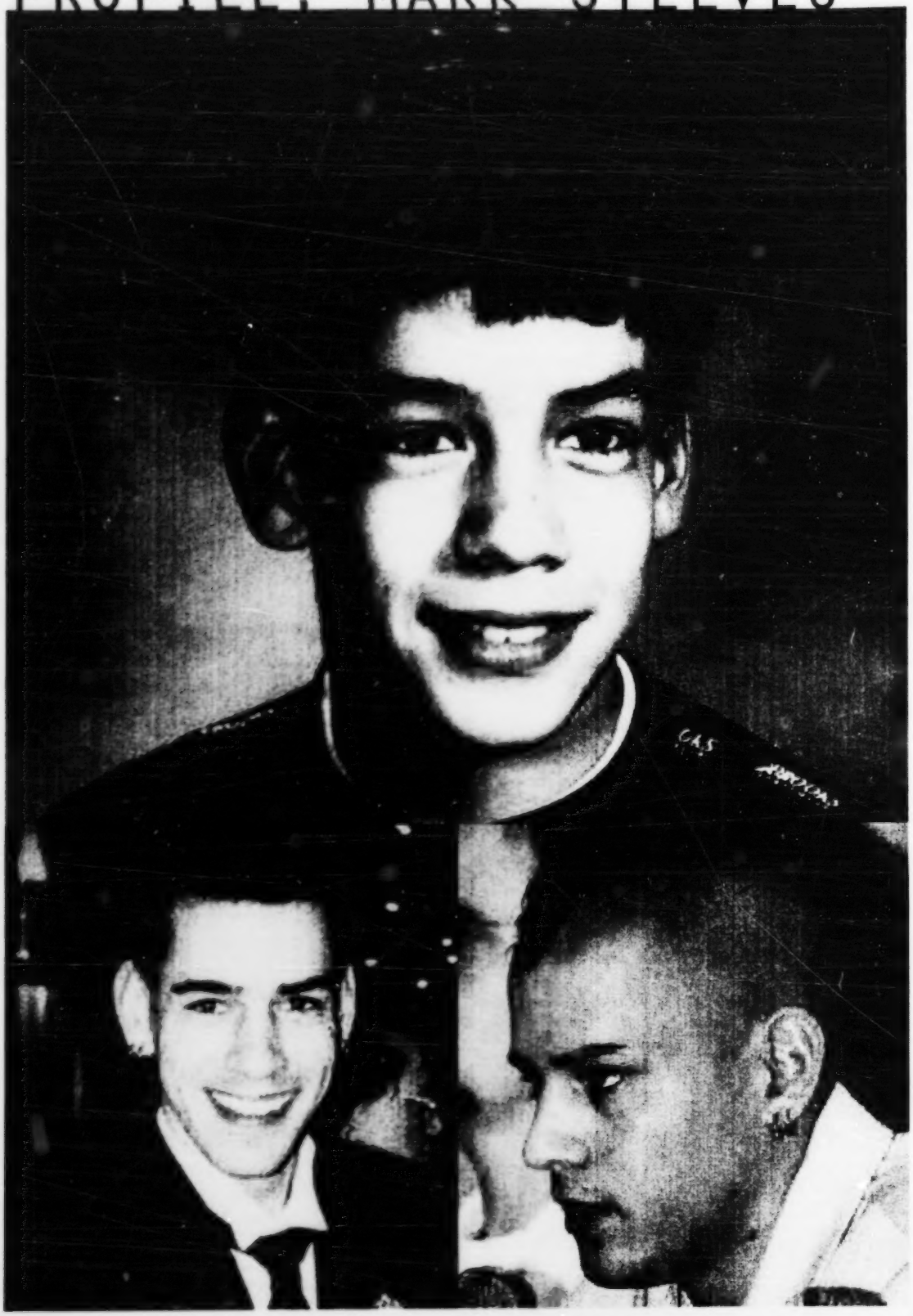
- In 2000, the Greater Vancouver FAS Society opened the Asante Centre for FAS in Maple Ridge. The centre provides diagnosis and assessment, prevention, care planning, research, training and support for professionals, and data collection. The Ministry for Children and Families is providing baseline funding for the centre, which is currently operating as a demonstration site.

From opening remarks at the forum by Sharon Manson Singer, Deputy Minister, Ministry for Children and Families


B.C. WAS THE FIRST PROVINCE TO
HAVE A STRATEGIC PLAN FOR FAS.
THE PLAN WAS DEVELOPED IN 1993
AND PROVINCIAL CO-ORDINATORS
HAVE BEEN IN PLACE SINCE 1995.
PREGNANCY OUTREACH PROGRAMS HAVE
BEEN AVAILABLE SINCE 1988.
A NATIONAL ADVISORY COMMITTEE ON
FAS WAS SET UP IN 2000.

A significant amount of work has gone into dealing with FAS in B.C.

PROFILE: MARK STEEVES



MARK STEEVES was 20 when he was diagnosed with FAS. Adopted as an infant, he was tested at age 10 because his parents knew he was having problems, but no mention of FAS was made at the time. Now 24, he says "It was only after I was diagnosed with FAS that professionals with experience with FAS were able to help me."

Mark, who is serving a conditional sentence at home, said he had trouble in school and has had a personal tutor since Kindergarten. "People with FAS learn differently from people without FAS. I thought I was really stupid," he says.

Mark started skipping classes in high school, but stayed on after his parents arranged for him to cook in the school cafeteria instead of attending classes so he wouldn't drop out. "I just wanted to learn to be a cook so I could get a job that wasn't about algebra and all that stuff."

Mark said he started getting into trouble in high school and saw his first lawyer at age 16. His lawyer wouldn't talk to his dad, because he said Mark was his client. This can cause a lot of problems for people with FAS. "Legal professionals must talk to parents or caregivers of FAS people. It doesn't matter how old we are. We often don't understand what we are being told or what we are signing."

Finding and keeping a job has its challenges, too. Mark had a good job as a cook in a restaurant, but was fired even though the manager said she liked his work. Mark's employer knew about his FAS but told his parents he was too much trouble and that they were running a business, not an employment program. "Someone has to work with employers of FAS people," Mark says. "They often don't understand the difficulties we have. We can do a good job, but employers have to understand us and learn about our disability."

5 SUPPORTING ABORIGINAL COMMUNITY ACTION

While FAS affects people of all origins and socio-economic backgrounds, limited studies of some Aboriginal communities suggest a rate of FAS that may be 10 times higher than in the general population. It is therefore essential to understand the origins of FAS and work with Aboriginal communities to prevent FAS and support those who have this disability.

FAS has had a devastating impact on Aboriginal communities in the Pacific region, sometimes resulting in the entire community being directly affected by families struggling to cope with the effects of FAS.

Because of the emotional and sensitive nature of the topic, FAS has traditionally been a hidden and unspoken disability. Denial stems from the relationship between this disorder and alcohol abuse in communities; people are afraid to address the underlying issues. Community leaders, lawyers and justice system workers are not sufficiently aware of the issues. Teachers and doctors often misinterpret behaviours associated with FAS, attributing them instead to Attention Deficit Disorder/Attention Deficit Hyperactive Disorder, which results in misdiagnosis. Unfortunately, addressing the problem is sometimes seen as blaming.

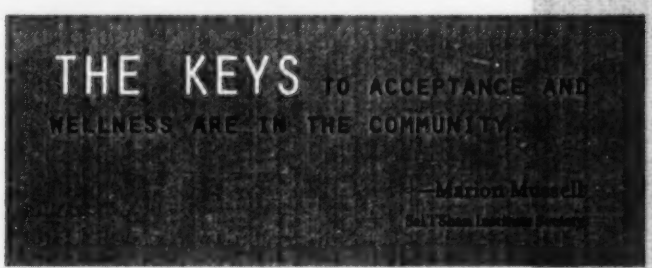
Because of the emotional and sensitive nature of the topic, FAS has traditionally been a hidden and unspoken disability.

Culturally relevant, holistic (i.e., interdisciplinary) and community-based FAS programs are needed. There is also a need to address the links between alcohol abuse and the legacy of residential schools, racism and other historical and current factors. Priorities for community action include:

- awareness
- access to support and education
- involvement of the family
- advocacy and case planning for affected children and adults
- "model programs" that are ready to deliver, and
- regular networking opportunities.

Aboriginal communities have a good sense of what they need to know and what they need to do. The work has to be community driven and community led. Outside agencies can support communities by appreciating the context of the issues, trusting the community's voice, and providing both human and financial resources to assist the community in its work.

From a presentation by Marion Mussell, Sal'I'Shan Institute Society, Chilliwack



PROFILE: JAN LUTKE

CHILDREN AND ADULTS WITH FAS HAVE PERMANENT, IRREVERSIBLE BRAIN DAMAGE — YOU DO NOT OUTGROW IT, AND YOU CANNOT FIX IT, LOVE IT AWAY, PUNISH IT AWAY, OR IGNORE IT AWAY. YOU CAN, HOWEVER, PROVIDE THE TYPES OF LONG-TERM INTERVENTION, SUPPORT, STRUCTURE AND SUPERVISION THAT ENCOURAGE, PROMOTE AND ALLOW ADEQUATE FUNCTION.

—Jan Lutke

Director of FACES, Society for the FAS/E Support Network of B.C., and adoptive mother of 12 children with FAS

MOTHER AND ADVOCATE

Jan Lutke is an adoptive parent of 12 children with FAS. Jan is also the director of FACES (Society for the FAS/E Support Network of B.C.). She says that the prevailing opinion in the public is that FAS is a moral issue. But, she says, "we are not bad parents with bad kids."

The needs of children with FAS are often misunderstood. Their actions need to be viewed as the product of a disability, not an act of will.

An intensive, co-ordinated approach is needed to respond to children with FAS over their life span. "We need to understand, respect and support their disability," she says, adding that parents with FAS children must "jump through hoop after hoop" to get adequate care and support. Affordable, available, accessible and knowledgeable help is needed, including:

- diagnostic and assessment services
- appropriate placement in foster homes
- properly supported adoptions
- educational supports, such as aides
- skilled support for parents.

"The proper response pays off in the long run," Jan says. When children and adults with FAS get the support and services they need, they are able to participate in society rather than just live on the fringes.

6 INNOVATION

Forum participants looked at two successful prevention projects—the Sheway Project and Healthier Babies, Brighter Futures in Burns Lake. Both projects clearly show that spending money on prevention and early intervention more than pays off. The success of these projects demonstrates that solutions to the problem of FAS lie in:

- changing the behaviours of women and men around alcohol use
- developing creative solutions with the alcoholic beverage industry
- educating young people about the potential dangers
- reaching pregnant mothers early—and even before pregnancy begins.

HEALTHIER BABIES, BRIGHTER FUTURES—BURNS LAKE

Healthier Babies, Brighter Futures is a community outreach program in Burns Lake, a small community in northern B.C. Approximately 40 per cent of the total population of 6,000 is Aboriginal.

The program has managed to connect with very hard-to-reach families. Client profiles at intake show that 83 per cent of women display FAS characteristics and behaviours.

When the program began, 100 per cent of the clients who came to the program were not on birth control, as it is difficult for people with FAS to remember to take a daily pill.

WE MUST LOOK WITH COMPASSION AT THE ROOT CAUSES OF FAS. MANY WOMEN WHO DRINK DURING PREGNANCY HAVE THEMSELVES BEEN ABUSED AND NEGLECTED AND MAY SIMPLY NOT KNOW HOW ALCOHOL CAN AFFECT THEIR UNBORN CHILDREN.

—Dr. Christine Loock

Developmental Pediatrician, Children's and Women's Health Centre of B.C., and Clinical Associate Professor, Department of Pediatrics, University of British Columbia

Community outreach has included going to the local pulp and paper mill to give presentations and raise awareness among the male population about the importance of not drinking during pregnancy. More than 4,000 people have attended FAS- and partial FAS–related workshops given by the program since 1998. All three pubs in Burns Lake now serve non-alcoholic drinks free of charge to pregnant women.

Results from the program in 1999 include:

- 100 per cent of clients accessed prenatal care
- 53 per cent of clients who delivered are now on reliable birth control
- 94 per cent of clients using alcohol/drugs abstained or cut down during pregnancy
- 96 per cent of clients maintained custody of their children
- 98 per cent of babies were born at a healthy birth weight.

Based on a presentation by Anne Price, Program Planner, "Healthier Babies, Brighter Futures"

Both projects clearly show that spending money on prevention and early intervention more than pays off.

ONE OF THE FIRST CLIENTS OF HEALTHIER BABIES, BRIGHTER FUTURES HAD A HISTORY OF CHILDHOOD SEXUAL ABUSE, COUPLED WITH NEGLECT, AN ALCOHOLIC HOME, POVERTY AND DOMESTIC VIOLENCE. SHE HAS PRENATAL ALCOHOL DAMAGE HERSELF AND WAS AN ALCOHOLIC BY AGE 16. SHE WAS SO FULL OF MISTRUST THAT IT TOOK FOUR ATTEMPTED VISITS BEFORE SHE ALLOWED ME IN THE DOOR AND SEVEN MORE TO CONNECT HER WITH A FAMILY SUPPORT WORKER (FSW). SHE WAS IN AN ABUSIVE SITUATION, WAS DRINKING HEAVILY, AND ROAMING FROM HOUSE TO HOUSE, AND HER FIRST CHILD WAS IN FOSTER CARE. BUT WE BELIEVED IN HER, AND WHENEVER SHE DID SOMETHING RIGHT, EVEN IF IT WAS ONLY A TINY, TINY THING, WE NOTICED.

SHE MADE INCREDIBLE HEADWAY IN A VERY SHORT PERIOD OF TIME. SHE QUIT DRINKING ALCOHOL AT ABOUT TWO MONTHS OF PREGNANCY. WHEN SHE TOLD HER FSW THERE WAS A WARRANT OUT FOR HER ARREST FOR A DRUG CHARGE, THE WORKER TOLD HER THAT THE BEST WAY TO STAY OUT OF JAIL WOULD BE TO TURN HERSELF IN. SHE WENT TO THE POLICE WITH HER FSW AND HER SOCIAL WORKER AND THE RCMP AGREED TO LET HER STAY OUT OF JAIL IF SHE AGREED TO STAY AT THE TRANSITION HOUSE AND STAY IN TOUCH WITH HER SOCIAL WORKER.

BECAUSE OF A DRASTIC CHANGE IN ATTITUDE FOR THE BETTER, SHE WAS ALLOWED TO HAVE HER FIRST CHILD BACK. HER FSW SUPPORTED HER IN GETTING HOUSING AND PERSONAL IDENTIFICATION. (ID OR LACK OF IT IS OFTEN A HUGE OBSTACLE FOR MANY OF OUR CLIENTS, WHO MAY MISPLACE OR LOSE IT; WITHOUT IT, THEY CAN'T ACCESS ADEQUATE HOUSING OR FINANCIAL SUPPORT.) HER FSW ALSO TOOK HER SHOPPING AND SHE LEARNED ABOUT GOOD NUTRITION.

SHE HAS PROVEN HERSELF TO BE A GOOD MOM, AND HAS RECENTLY ENROLLED IN SCHOOL TO WORK TOWARD HER GRADE 12. OUR HOPE IS THAT WITH SUPPORT SHE'LL CONTINUE TO DO WELL AND BREAK THE CYCLE OF ABUSE, NEGLECT AND FAS.

—Anne Price

SHEWAY PROJECT— DOWNTOWN EASTSIDE, VANCOUVER

Sheway is an innovative, multidisciplinary pregnancy outreach service located in Vancouver's Downtown Eastside. Sheway uses a team approach to build trust with its clients, providing holistic services for pregnant women with substance use problems, and support for mothers and their families until their children are 18 months of age. The service promotes the well-being of pregnant women and their families, taking into consideration the context of life in the Downtown Eastside of Vancouver, one of Canada's poorest neighbourhoods, renowned for its high crime rate, drug and sex trade, violence, substandard housing and high rate of HIV. Sheway takes a woman-centered, harm-reduction, culturally focused approach to providing services. The cornerstone of the Sheway philosophy is "Mother the mother, and she will mother the child."

A 1999 evaluation of Sheway's services undertaken by the B.C. Centre of Excellence for Women's Health with funding from Health Canada showed that:

- 30 per cent of women had no medical/prenatal care at intake, whereas 91 per cent of women were connected to a physician or midwife by the time of their deliveries
- 79 per cent of women who were accessing services had nutritional concerns at intake, whereas only four per cent had nutritional concerns at six months post-natal
- 27 per cent of women had no fixed address at intake and 65 per cent had housing concerns at intake; by six months post-natal, those having housing concerns were reduced to six per cent
- 86 per cent of the babies whose mothers received care at Sheway were known to have a healthy birth weight of over 2,500 grams, up 20 per cent from 1993
- more than half (58 per cent) of mothers did not have problems with retaining custody of their children (22 per cent had no involvement by the Ministry for Children and Families and 36 per cent had ministry involvement for support only); the remaining 42 per cent of mothers had their children apprehended, yet 37 per cent of these babies were later returned to the care of the birth mother or her immediate family— a significant improvement over 1993, when virtually all children of mothers identified as high-risk were being apprehended.

Based on a presentation by Nancy Poole, Research Consultant, B.C. Centre of Excellence for Women's Health and Evaluator, Sheway Project, and Dana Clifford, Sheway Project staff member

7 TAKING ACTION

RESPONSIBILITY

UNDERSTANDING, COMPASSION AND HOPE ARE THE UNDERLYING PRINCIPLES OF ALL THE WORK WE DO ON FAS.

—Dr. Christine Loock

Mark, Ranada and Kirk told the other forum participants why it is time for action. These three young adults live meaningful and productive lives, but they have had to endure hardships that could have been avoided if services and supports had been co-ordinated and relevant to their needs. Their families have also dealt with unnecessary stress as they "jump through hoops" to get their children the support they have a right to. Many other children and youth with FAS have not received the support and services they need and are at great risk.

The cost of waiting until a crisis erupts will be huge. In comparison, the cost of prevention is minimal, as is the cost of early intervention and helping children and families learn to cope with FAS.

B.C. developed a strategic plan for dealing with FAS in 1993. Since that time, some important progress has been made. Provincial initiatives include:

- the provincial FAS co-ordinator position
- making information on FAS part of training activities for many professionals
- the Provincial FAS Consultation Group, to enhance information sharing among service providers and experts
- the FAS Community Action Guide, to assist communities in developing prevention and support initiatives that work for them
- hospital discharge guidelines for infants with FAS
- base funding for a new diagnostic and support centre
- Building Blocks initiatives intended to reach at-risk women
- pregnancy outreach programs
- resolutions passed by municipalities requiring drinking establishments to post signs warning pregnant women about the dangers of drinking.

While these are positive steps, gaps and barriers still exist and must be addressed.

AN FAS ACTION PLAN FOR B.C.

The Children's Commission therefore recommends that the Ministry for Children and Families take the lead in implementing a comprehensive FAS action plan that incorporates the key elements recommended by the Children's Commission. The ministry should include representatives from key areas of government, as well as advocates and experts in the area of diagnosis and treatment of people with FAS, in planning for implementation of the plan.

KEY ELEMENTS OF B.C.'S FAS ACTION PLAN

1. PREVENTION

FAS is preventable. Prevention therefore represents savings in terms of dollars, and more importantly in human life.

The Children's Commission recommends that:

- public education campaigns be developed, aimed at ensuring that all British Columbians understand what FAS is and how to prevent it
- the B.C. Liquor Licensee and Retailers Association, B.C. Restaurant and Food Services Association, and B.C. Hotel Association be contacted to partner in a province-wide initiative that would encourage all establishments that serve alcohol to:
  - train their servers about the dangers of drinking during pregnancy
  - provide pregnant women with free non-alcoholic drinks
  - display information about responsible consumption of alcohol
- pregnant women be ensured access to alcohol treatment programs
- Aboriginal communities be supported in identifying the underlying causes of FAS and developing their own solutions
- there be increased support for prevention programs such as Sheway and the Burns Lake Healthier Babies, Brighter Futures
- the Ministry for Children and Families, the Ministry of Education, and school districts work together to ensure that the

curriculum provides junior high and high school students with adequate information about the dangers of alcohol consumption during pregnancy.

In addition, and very importantly, the province and the federal government must continue their efforts to address related factors that compromise an individual's health and contribute to the occurrence of FAS—namely, poverty, tobacco use, drug use, poor nutrition and lack of prenatal care.

2. DIAGNOSIS AND SUPPORT

Diagnosis is a blueprint for action. We need to shift to a new paradigm for diagnosing and supporting people with FAS—one based on the view that FAS is a disability that requires action to be taken. Early intervention and ongoing, appropriate support reduce the costs of FAS, both human and financial, and the likelihood of future problems occurring.

The Children's Commission therefore recommends that:

- at least two more diagnostic and support centres be established, particularly in the North and on Vancouver Island, to help ensure that services are accessible and affordable
- physicians have information and readily available consultation with experts in order to recognize and support FAS
- there be an ongoing inventory of current support services, to identify gaps and develop solutions to address them
- skilled help is provided in all regions for adoptive and foster parents which focuses on the particular challenges of caring for a child or youth with FAS
- services, supports and facilities are developed that meet the needs of offenders with FAS
- services are provided for children and youth with FAS and their families that meet their particular needs, rather than basing the level and type of service provided solely on IQ scores
- pilot projects be implemented and evaluated with the aim of learning how best to assist youth with FAS in making the transition to adulthood.

3. COMMUNITY ACTION

Preventing FAS and ensuring that children and youth with FAS and their families are welcomed in communities is about community action. Solutions to FAS must be community-based. The Burns Lake and Sheway projects are examples of communities working in partnership with government to provide relevant and needed services that are specific to the needs of the community.

Just like other children, children and youth with FAS need recreational, learning and employment opportunities. In order for this to happen, communities need to understand that people with FAS are capable of being productive members of society if they get the support and understanding they need.

The Children's Commission therefore recommends that all regions be provided with assistance in developing a co-ordinated action plan for assisting children and youth with FAS and their families. This planning must involve:

- school districts
- regional and community health authorities
- Ministry for Children and Families regional offices
- regional corrections offices
- relevant community organizations
- local governments, and
- Aboriginal communities.

4. ENSURING THAT PROFESSIONALS HAVE KNOWLEDGE AND TRAINING

As Mark, Ranada and Kirk explained, people with FAS are too often viewed as lazy, lacking in intelligence and irresponsible. Obviously this is not the case. People with FAS need skilled caregivers who know how to help them learn and function in the world.

FAS is a relatively new discovery. Education programs need to keep up with information about FAS as it emerges.

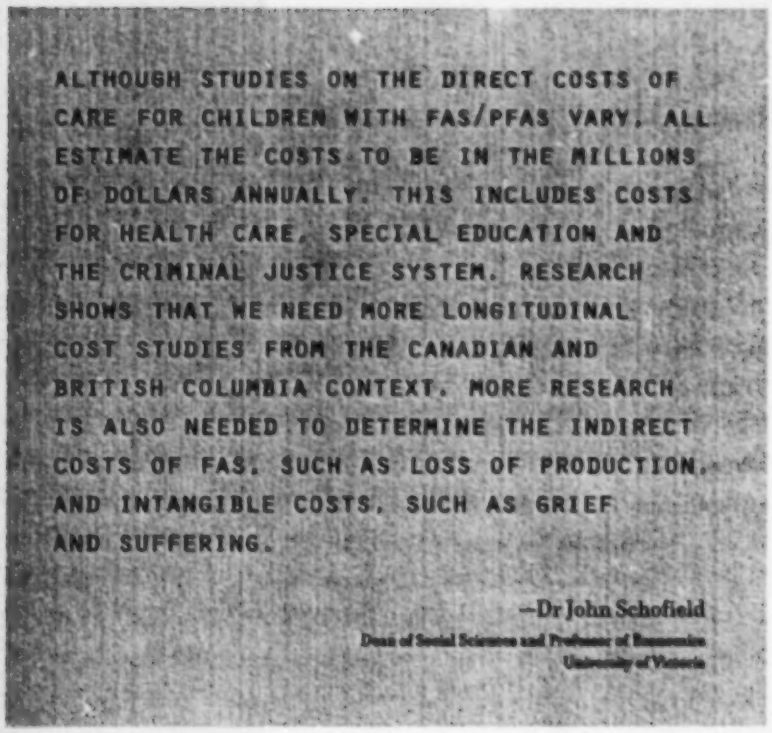
To ensure that young people like those who came to the forum get the help they need, the Children's Commission recommends that post-secondary institutions, school boards, relevant ministries, unions and regulating bodies be contacted to ensure that FAS training is provided for a wide range of professionals (e.g., doctors, nurses, social workers, teachers, lawyers) at the undergraduate, pre-service and in-service levels, and to ensure that they understand FAS and are accurately informed of the best ways to support those affected.

5. MAKING BETTER USE OF RESOURCES

The key to implementing an effective, accountable FAS action plan is the establishment of a mechanism to ensure information-sharing about available services and supports and lessons learned. Federal and provincial government ministries and departments, service providers, and those affected by FAS must be involved, and information must be shared inter-provincially, provincially, regionally and at the community level.

The Children's Commission therefore recommends:

- development of an easily accessible, interactive clearinghouse for information on FAS
- establishment of an organized and effective means for B.C. to link with programs and initiatives in other provinces
- co-ordination of addiction professionals' efforts regarding FAS with those service providers concerned with prenatal and reproductive care and maternal and child health, and with other health care professionals.


ALTHOUGH STUDIES ON THE DIRECT COSTS OF CARE FOR CHILDREN WITH FAS/PFAS VARY, ALL ESTIMATE THE COSTS TO BE IN THE MILLIONS OF DOLLARS ANNUALLY. THIS INCLUDES COSTS FOR HEALTH CARE, SPECIAL EDUCATION AND THE CRIMINAL JUSTICE SYSTEM. RESEARCH SHOWS THAT WE NEED MORE LONGITUDINAL COST STUDIES FROM THE CANADIAN AND BRITISH COLUMBIA CONTEXT. MORE RESEARCH IS ALSO NEEDED TO DETERMINE THE INDIRECT COSTS OF FAS, SUCH AS LOSS OF PRODUCTION, AND INTANGIBLE COSTS, SUCH AS GRIEF AND SUFFERING.
—Dr John Schofield

6. Research and Evaluation

We need more and better information about FAS—its prevalence, costs, promising strategies and interventions, and lessons learned. We must be able to determine whether our efforts are making a difference for children and youth with FAS and their families.

The Children's Commission therefore recommends:

- research be undertaken to:
  - more accurately identify FAS in all populations
  - identify those most at risk
  - determine the relationship between other factors and fetal and child health
- establish a formalized commitment to program evaluation, which will include:
  - supporting the federal government's research and evaluation (through the recently established Centre of Excellence on Children and Youth with Disabilities)
  - encouraging the academic community to increase efforts in this area
  - increasing the provincial government's research and evaluation of FAS programs and services

- conduct a study on the feasibility of providing consumer information on alcohol beverage products.

THE ROLE OF THE CHILDREN'S COMMISSION

In addition to having hosted the forum and prepared this report, the Children's Commission will:

- support the action plan by providing data and information
- monitor implementation of the action plan
- report publicly on progress in October 2001 and regularly thereafter, and
- continue to advocate for prevention and for services for children and youth with FAS and their families.

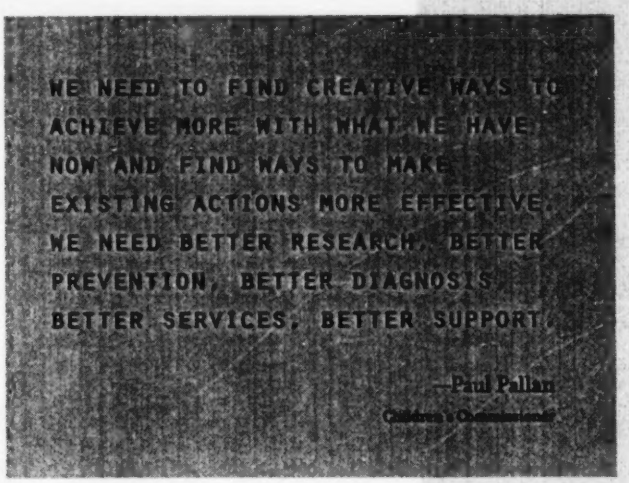
COMMITMENT, LEADERSHIP AND POLITICAL WILL

B.C. has nationally recognized experts who have demonstrated leadership in research, education and training, prevention and support. Solving the problems associated with FAS requires ongoing commitment and strong leadership from these experts and from government.

Support for B.C.'s FAS action plan must:

- come from the highest level of government
- be ongoing, consistent and persistent, and
- be backed by adequate resources.

We know what needs to be done. Supporting the action plan is not a cost, it's an investment. The choice is clear: we can pay now, or we can pay a lot more later.


WE NEED TO FIND CREATIVE WAYS TO ACHIEVE MORE WITH WHAT WE HAVE NOW AND FIND WAYS TO MAKE EXISTING ACTIONS MORE EFFECTIVE. WE NEED BETTER RESEARCH, BETTER PREVENTION, BETTER DIAGNOSIS, BETTER SERVICES, BETTER SUPPORT.
—Paul Pallan

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c/o Ktunaxa Independent School System

TAMMIE WYLIE
Project Manager
Seeking Alternatives

APPENDIX B: WHERE TO GET MORE INFORMATION ON FAS

The Asante Centre for Fetal Alcohol Syndrome
22326(A) McIntosh Avenue
Maple Ridge BC V2X 3C1
Tel: (604) 467-7101
Fax: (604) 467-7102
e-mail: info@asantecentre.org
Web: www.asantecentre.org

The Asante Centre provides diagnostic, assessment and support services for children, youth and adults affected by FAS. Co-ordinated care plans are established to focus on working in partnerships with families and recognizing the value of their experience in understanding and planning their child's or adult's future. Unique on-site training, consultation and observation are also offered for professionals and paraprofessionals.

BC FAS Community Action Guide
c/o Adult Addiction Services
PO Box 9717
Stn Prov Govt
Victoria BC V8W 9S1
Tel: (250) 953-3113
Fax: (250) 953-3044
Web:
http://www.mcf.gov.bc.ca/child_protection/fas/fas_index.htm
Published in 1998, this guide is designed to support those working on FAS prevention and early intervention in communities across B.C.

B.C. FAS Resource Society
c/o Sunny Hill Health Centre for Children
3644 Slocan Street
Vancouver BC V5M 3E8
Tel: (604) 467-5591

The society encourages the provision of information, support and services for families, professionals and the broader community around prevention, intervention and treatment issues relating to FAS/PFAS and other disabilities caused by alcohol and drug use during pregnancy.

B.C. Aboriginal Network on Disability Society
Resource Information Centre
1179 Kosapsum Crescent
Victoria BC V9A 7K7
Tel: (250) 381-7303; 1-888-815-5511 (toll free in Canada)
Fax: (250) 381-7312
E-mail: jeanwylie@home.com

The Resource Information Centre provides information, resources and referral in response to requests, and undertakes community awareness activities.

B.C. Council for Families
204-2590 Granville Street
Vancouver BC V6H 3H1
Tel: (604) 660-0675
Fax: (604) 732-4813
E-mail: bccf@istar.ca

The B.C. Council for Families provides "train the trainer" training for community groups for "Ready or Not," a parent education program for parents of children ages 8–12. The goal is to provide parents with more effective parenting skills, and to help them prevent drug and alcohol use by their children.

CAPC/CPNP Regional Programs
Health Promotion and Programs Branch
44F-757 West Hastings Street
Vancouver BC V6C 1A1
Tel: (604) 666-2729 Fax: (604) 666-8986
E-mail: denise_weber@hc-sc.gc.ca
Web: http://www.hc-sc.gc.ca

CAPC (Community Action Program for Children) and CPNP (Canada Prenatal Nutrition Program) are programs delivered through Health Canada regional offices. CAPC delivers services that address the developmental needs of at-risk children from birth to six years of age. CPNP is designed to provide food supplementation, nutrition counselling, support, education, referral and counselling on lifestyle issues for pregnant women at risk. Programs are available throughout the province and are community based.

FAS/E Support Network of B.C.
13279 72nd Avenue
Surrey BC V3W 2N5
Tel: (604) 507-6675
Fax: (604) 507-6685
E-mail: fasnet@istar.ca
Web: http://www.fetalalcohol.com

The FAS/E Support Network provides consultation, education and support services and undertakes research projects in the area of FAS. Consultation and support services are under contract to the province of B.C., Ministry of Children and Families, and are offered free of cost to users. Training services are available on a fee-for-service basis. Publications available for purchase include a newsletter, "About FASE," four times per year; a series of six age-appropriate FASNET screening tools; "A layman's guide to Fetal Alcohol Syndrome and possible fetal alcohol effects"; "Dear world: We have fetal alcohol syndrome—Experiences of young adults"; "FAS/E and education: The art of making a difference"; 'My name is Amanda and I have FAE"; "So your child has FAS/E: What you need to know."

Health Services for Community Living
Preventive Health Branch
1520 Blanshard Street, Main Floor
Victoria BC V8W 3C8
Tel: (250) 952-1528
Fax: (250) 952-1570
E-mail: jirussel@bcsc02.gov.bc.ca

Health Services provides medical consultation for persons with mental/developmental disability and will assist clients in obtaining nursing and therapy health services on Vancouver Island and in the Interior and North regions of B.C.

Health Services for Community Living
c/o Radiation Protection Branch
210-4940 Canada Way
Burnaby BC V5G 4K6
Tel: (604) 660-0782
Fax: (604) 660-6663
E-mail: brian.plain@moh.hnet.bc.ca

Health Services provides medical consultation for persons with mental/developmental disability and will assist clients in obtaining nursing and therapy health services in the Lower Mainland, Fraser Valley and Sunshine Coast areas of B.C.

Infant Development Program of British Columbia
2765 Osoyoos Crescent
Vancouver BC V6T 1X7
Tel: (604) 822-4014
Fax: (604) 822-9556
E-mail: infantdv@interchange.ubc.ca

Infant Development Programs in B.C. provide home visits and group experiences for families with children aged birth through three years at risk for, or living with, a developmental challenge. For families with a child with FAS or where a parent has FAS, information and support is given to the family that will promote the child's development and strengthen family capacity.

Pregnancy Outreach Program (POP)
737 Courtney Street, 3rd Floor
Victoria BC V8W 1C2
Tel: (250) 356-5884
Fax: (250) 952-6059
E-mail: deborah.leach@gems6.gov.bc.ca

POP promotes positive health practices and works towards decreasing alcohol consumption and supporting and encouraging abstinence. It also seeks to identify women at risk for alcohol abuse and refers clients to appropriate counselling and intervention.

Prevention Source BC
210-2730 Commercial Drive
Vancouver BC V5N 5P4
Tel: (604) 874-8452;
1-800-663-1880 (toll free in B.C.)
Fax: (604) 874-9348
E-mail: info@psbc.bc.ca
Web: http://www.preventionsource.bc.ca

Prevention Source BC develops alcohol, tobacco and other drug prevention resources and disseminates information to service providers and the public in B.C.

Provincial FAS/NAS Early Intervention Consultant
The Aurora Centre, 5th Floor
4500 Oak Street
Vancouver BC V6H 3N1
Tel: (604) 875-2017
Fax: (604) 875-2039
E-mail: jamos@cw.bc.ca

The early intervention consultant works with health and social service providers towards the provision of improved early intervention approaches with women at risk and gathers and disseminates information on effective early intervention strategies and appropriate and accessible treatment for women using alcohol and other drugs during pregnancy.

Provincial FAS Prevention Consultant
Women's Health Centre
5th Floor, Room E501
4500 Oak Street
Vancouver BC V6H 3N1
Tel: (604) 875-3599
Fax: (604) 875-2039

The prevention consultant is responsible for promoting and supporting a network of information and expertise on FAS/ADRDD prevention among programs and projects throughout the province; providing information and referral services for the public and professionals on how to access related resources, expertise and services; and providing technical support for groups and organizations initiating activities at the community level.

Safe Babies Program
Ministry for Children and Families—
Residential Resources
P.O. Box 9710, Stn Prov Govt
2814 Nanaimo Street
Victoria BC V8W 9S1
Tel: (250) 953-3711
Fax: (250) 953-3710

The Safe Babies Program provides education, consultation and support for birth families, alternative caregivers and professionals about substance-exposed infants, and assists communities in preparing general awareness and specialty training programs for those parenting or working with substance-exposed infants.

Sal'i'Shan Institute Society
P.O. Box 242
800 Wellington Avenue
Chilliwack BC V2P 6J1
Tel: (604) 792-7300
Fax: (604) 792-5498
E-mail: salishan@dowco.com

The Sal'i'Shan Institute Society provides education and training programs for community health workers and addiction counsellors who may work with fetal alcohol–affected persons, with a primary focus on prevention and intervention.

Society For Special Needs Adoptive Parents (SNAP)
1150-409 Granville Street
Vancouver BC V6C 1T2
Tel: (604) 687-3114 or 1-800-663-7627
Fax: (604) 687-3364
E-mail: snap@sanp.bc.ca

SNAP maintains a resource library with hundreds of FAS/pFAS resource books, periodicals, videos and cassette tapes. SNAP also has FAS-specific support groups throughout the province.

Sunny Hill Health Centre for Children
Children's and Women's Health Centre of B.C.
3644 Slocan Street
Vancouver BC V5M 3E8
Tel: (604) 453-8300
Fax: (604) 453-8301

Sunny Hill provides both inpatient and outpatient services for children (up to 19 years of age) and their families where questions have arisen around the possible impact of prenatal exposure to alcohol and/or other drugs. Service may take the form of consultation and initial linking to available community resources; diagnosis and developmental assessment; medical and social support for inpatient infants experiencing withdrawals; and education and advocacy, with community education being a vital component of clinical outreach.